

# SURVEY 2014



**nras**  
National Rheumatoid  
Arthritis Society

in collaboration with

**2020**  
**HEALTH**  
WELLBEING  
RESPONSIBILITY



## Invisible Disease

.....  
Rheumatoid Arthritis  
and Chronic Fatigue

“It’s difficult explain to my toddler that I’d rather sit on the sofa than go to the park with her.”







# nras

National Rheumatoid  
Arthritis Society

NRAS is the only user-led charity in the UK specifically for people with rheumatoid arthritis, their families and carers, providing information, support, advocacy and campaigning.



- The NRAS freephone helpline **0800 298 7650** is open from 9.30am to 4.30pm Monday to Friday. Trained helpline staff answer questions on all aspects of living with RA, with support from our medical and allied health professional advisers.



- Our website **[www.nras.org.uk](http://www.nras.org.uk)** has a wealth of information about living with RA, treatments, the latest research and developments, and an online members' forum. It also has a full list of links to other useful charities and organisations.



- If you'd like to talk on the phone to another person who has RA, we can put you in touch with one of our trained volunteers – people with RA who understand what you're going through. They're available at the end of the phone to chat and listen. To arrange for someone to contact you, call us on **0800 298 7650**.



- Local NRAS groups meet regularly around the country. To find out if there is a group near you, call **0845 458 3969** or visit **[www.nras.org.uk/groups](http://www.nras.org.uk/groups)**



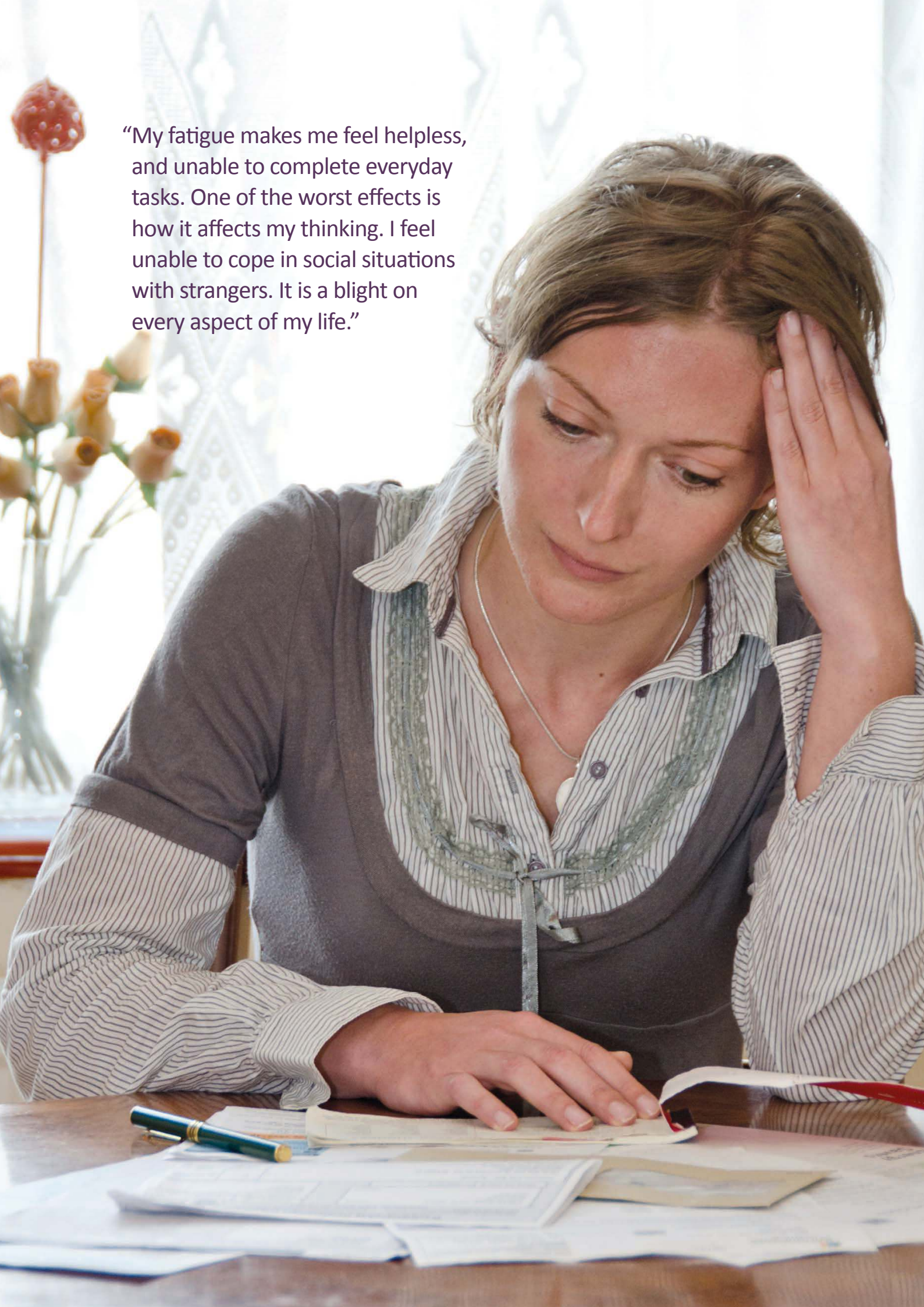
To help NRAS continue this vital work please support us by:

- Becoming a member
- Participating in or planning a fundraising event
- Donating today – every penny counts.

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“My fatigue makes me feel helpless, and unable to complete everyday tasks. One of the worst effects is how it affects my thinking. I feel unable to cope in social situations with strangers. It is a blight on every aspect of my life.”



# Contents

<b>1</b>	<b>Introduction</b>	<b>6</b>
<b>2</b>	<b>Executive summary</b>	<b>8</b>
<b>3</b>	<b>Background to the survey</b>	<b>10</b>
	3.1 Chronic fatigue and rheumatoid arthritis – evidence and policy	10
	3.2 Definition	10
	3.3 Causes	10
	3.4 Impacts on quality of life	11
	3.5 Impacts on work	12
	3.6 Management of chronic fatigue	14
	3.7 Measurement of chronic fatigue	14
	3.8 Treatment of chronic fatigue	15
	3.9 Public awareness	15
	3.10 Government policies	16
	3.11 Implementation	18
	3.12 Calls for action	19
	3.13 Survey and its methodology	20
<b>4</b>	<b>Key findings</b>	<b>22</b>
	4.1 The survey respondents	22
	4.2 About your fatigue	24
	4.3 Public awareness	25
	4.4 Quality of life	26
	4.5 Fatigue and work	29
	4.6. Management of fatigue	33
	4.7 What would help	34
<b>5</b>	<b>Conclusions and Recommendations</b>	<b>36</b>
	5.1 Survey findings	36
	5.2 Recommendations	36
<b>6</b>	<b>Thank you</b>	<b>38</b>
<b>7</b>	<b>References</b>	<b>39</b>



# Introduction



Ailsa Bosworth

*Chief Executive, National Rheumatoid Arthritis Society*

To coincide with the launch of our second Rheumatoid Arthritis Awareness Week, and this year's theme of 'Invisible Disease', we have collaborated with leading think tank 2020health to conduct a national survey to try and better understand the impact of chronic fatigue on the lives of people with the chronic autoimmune disease rheumatoid arthritis (RA).

In keeping with our tradition of publishing original research, we believe this is the first time that so many people with RA across the UK have been surveyed about their experiences of chronic fatigue – including their views about levels of public awareness of the symptom, the effectiveness of existing management approaches, the impact of chronic fatigue on their quality of life and work outcomes.

The results from the survey are eye-opening. The survey respondents' ranked chronic fatigue as the least understood symptom of RA by the public. Nine out of ten survey respondents said they suffered with chronic fatigue, of which nearly two-thirds said onset appeared before diagnosis. Equally troubling, the majority of respondents said they experienced chronic fatigue on three or more days during the previous week and that this lasted for several hours at a time. Over three quarters of respondents said chronic fatigue had a high or medium level impact. Two thirds of all respondents said their healthcare professional never or rarely asked them about their fatigue and over three quarters had never attempted to measure it.

Due to the symptom severity described by respondents, the work impacts were also significant. Just under three-quarters of working age people with RA who were not in work said that chronic fatigue had contributed to their unemployment. Nearly a quarter of respondents said they had changed job due to their chronic fatigue. Overall, nearly a third of all respondents had taken time off work during the previous week because of their fatigue and one in ten of all respondents in work said they had taken off more than 10 hours.

Consequently, there are a number of important implications arising from the report. First of all, if we are to improve levels of public awareness and rates of early diagnosis we must develop better messaging about the symptom of chronic fatigue within awareness campaign materials about inflammatory arthritis, because it is clearly being overlooked and this may in turn be contributing to delays in patients presenting to their GPs.

Secondly, it should be abundantly clear from the report's literature review and accompanying survey results that references to the management of chronic fatigue need to be strengthened within the relevant RA clinical guidelines and that further resources urgently need to be put in place to help healthcare professionals deliver improved care.

Finally, as described in the report, the widespread impact that chronic fatigue has on work outcomes and the inadequate way it is captured during the Employment and Support Allowance assessment process, means there is a strong case for reform.

*Invisible Disease: RA and Chronic Fatigue* forms part of NRAS's ongoing commitment to campaign for equal access to good care and services for all.

“In keeping with our tradition of publishing original research, we believe this is the first time that so many people with RA across the UK have been surveyed about their experiences of chronic fatigue.”

## Julia Manning

*Chief Executive, 2020health*

The findings of this survey make compelling reading. They remind us just how much more we need to do to ensure that people suffering with RA are able to lead happy and fulfilling lives while managing the effects of chronic fatigue. The survey resonated with us on a number of levels, but two areas in particular are most striking and relevant to our work at 2020health: firstly, the numbers of people who experienced difficulty working and staying in the workplace, and secondly, those reporting that the effects of their chronic fatigue were not addressed by professionals. Whilst sadly not surprising, these are areas that needs urgent attention.

Hidden from our sight, this debilitating disease leads many people into 'worklessness', isolation and depression. This report highlights existing evidence that most sufferers are diagnosed when of working age but within four years only 10% are completely free of any impact on their work. Shockingly, around two thirds of people with RA who are employed have experienced work loss as a result within the last 12 months. In 2020health's publication 'Work as health outcome in the Devolved Nations' (2012) we made the point that the "impact of sickness related 'worklessness' is a blight on individuals, families, communities and economies". The fact that so many people end up dependent on benefits through this disease is, itself, a call to action.

We also noted in our 'Working together: promoting work as a health outcome as the NHS reforms' (2011) that employers are well placed to take a leading role in reducing worklessness through supporting employees so they did not need to take time off work, and facilitating the return to work of the unemployed. Yet almost half of the people surveyed by the NRAS had never had any discussion with employers about how to facilitate improving their working lives. In our same report we noted that tackling stigma within an organisation with regard to ill-health was important, and this is reflected in the NRAS respondents' concerns that colleagues did not understand the effect chronic fatigue has on an individual's ability to carry out their tasks. The very nature of the disease means that the ups and downs can be misconstrued by unknowing colleagues as laziness. The call for more support in the workplace was made loud and clear in the survey results.

Our final thoughts turn to those reporting that their rheumatologist, GP or nurse rarely or never asked about their fatigue. Almost half of respondents had never discussed their fatigue with a healthcare professional. Given the impact that chronic fatigue has on the lives of people with RA it is disappointing that clinical teams place less emphasis on this area of their patients' management. If, as the survey suggests, this is an area where many would benefit from additional support and treatment, it is essential that the professionals focus on helping sufferers manage their chronic fatigue. Chronic fatigue as a condition in itself has become widely recognised, with specialist support and advice available from nurses, occupational therapists, physiotherapists and psychologists.

Today there are any number of ways in which people can access support, yet this research has identified that many patients are still not signposted by professionals to the NRAS, the very charity established to support and encourage them. The importance of making sure healthcare professionals are fully trained and follow guidelines is essential, but enabling them to assist RA sufferers with chronic fatigue to seek out help and support should also be improved. This report creates a greater understanding and focus on chronic fatigue and through their efforts, NRAS and others, are empowering this group of patients, by giving them the information and voice they need.



**"Today there are any number of ways in which people can access support, yet this research has identified that many patients are still not signposted by professionals to the NRAS, the very charity established to support and encourage them."**

## 2 Executive summary

“Chronic fatigue is an invisible symptom of the disease that can have a severe impact. It is a major concern for patients and 40% may experience persistent, severe fatigue comparable to Chronic Fatigue Syndrome.”

Rheumatoid arthritis (RA) is a chronic, progressive and disabling disease where the immune system attacks the synovial lining to the joints and other organs. If left untreated, the joint can lose its shape and alignment, cause bone erosion and ultimately lead to destruction of the joint and permanent disability. It is a systemic disease, which means it can also affect internal organs of the body such as the heart, eyes and lungs.

Nearly 690,000 people across the UK have RA. For some people, the disease is moderate or less severe and remains reasonably well controlled, but others experience chronic disabling pain, inflammation, stiffness, chronic fatigue, reduced joint function and impaired mobility.

Quality of care and access to treatments for people with RA varies tremendously around the UK, which in many cases is exacerbating poor health outcomes for patients and placing a heavy economic burden on society. Overall, a quarter of people with RA give up work due to their disease within one year of diagnosis and over half stop within six years. The additional cost of RA to the UK economy, including sick leave and work-related disability, is estimated to be £3.8 to £4.8 billion a year.

Chronic fatigue is an invisible symptom of the disease that can have a severe impact. It is a major concern for patients and 40% may experience persistent, severe fatigue comparable to Chronic Fatigue Syndrome. Despite this, chronic fatigue is the least publicly understood symptom of RA, with only 31% of the British public being able to identify it as a symptom of the disease.

This report details the wide-ranging and significant impacts that chronic fatigue has on quality of life and work for people with RA. Much more needs to be done to measure and treat this aspect of the disease, to mitigate its impact on work and daily life, and to promote messages about chronic fatigue in public awareness campaigns about the disease symptoms, which encourage early diagnosis.

### Key findings

- Chronic fatigue is widespread among RA patients: 89% of respondents experienced chronic fatigue and 98% of these said it impacted on their lives during the previous 7 days; 94% of respondents said their episodes of chronic fatigue lasted either for several hours or all day.
- More needs to be done to raise public awareness of chronic fatigue as a symptom: 57% of respondents said their chronic fatigue first appeared before they were diagnosed with RA and 76% of respondents felt the public is not at all aware that it is symptom of RA.
- Chronic fatigue is having a large impact on ability to work: 71% of working age respondents that were unemployed said chronic fatigue contributed to them not being able to work and 24% of respondents said they had to change jobs as a result of their chronic fatigue.
- Employers need to do more to help: 23% of respondents in employment took more than 10 days off in the last 12 months due to chronic fatigue; but 49% of respondents said their line manager had not discussed or offered any changes to help them better manage their chronic fatigue in the workplace.



- Chronic fatigue is having a high impact on mental health: 90% of respondents said fatigue caused them to feel down or depressed during the last 7 days, including 38% who said they felt very down or depressed; 48% said they feel guilty about its impact on other people.
- Chronic fatigue is having a high impact on relationships: 70% of respondents reported that fatigue had prevented them from taking part in activities with their family or partner; and 54% reported that fatigue negatively affected their sex life.
- Chronic fatigue is not being well managed by healthcare professionals: 66% of respondents said their healthcare professional never or rarely asks them about its effect; and 79% of respondents said their healthcare professional has never tried to measure their levels of fatigue.
- People with RA need much better access to treatments for chronic fatigue: 16% of respondents said they do nothing to manage their fatigue; and only 2% of respondents have attended a chronic fatigue self management programme.

## Recommendations

- The governments of England, Scotland, Wales and Northern Ireland urgently need to initiate public awareness campaigns about RA, which must include specific messaging about the presence of chronic fatigue as a symptom.
- Important medical guidelines for healthcare professionals, such as NICE Clinical Guideline 79 and SIGN Guideline 123, need to be revised to prioritise effective management of chronic fatigue in RA, including the introduction of validated fatigue measures.
- Patient education and self-management strategies should be prioritised for people with RA in relevant medical guidelines and within government policies for long term conditions across England, Scotland, Wales and Northern Ireland.
- More should be done to raise awareness amongst employers of the impact and challenges posed by chronic fatigue within RA, and how it can be managed in the workplace.
- The introduction of an additional descriptor into the Employment Support Allowance's Work Capability Assessment to ensure the impact of chronic fatigue is adequately captured.

# 3 Background to the survey

“The causes of chronic fatigue in RA are complex and not well understood, with a number of possible factors associated with its occurrence and severity.”

## 3.1 Chronic fatigue and rheumatoid arthritis – evidence and policy

Rheumatoid arthritis (RA) is a chronic, progressive and disabling disease where the immune system attacks the synovial lining to the joints and other organs. If left untreated, the joint can lose its shape and alignment, cause bone erosion and ultimately lead to destruction of the joint and permanent disability. It is a systemic disease, which means it can also affect internal organs of the body such as the heart, eyes and lungs.

There are nearly 690,000 people across the United Kingdom with RA. For some people, the disease is moderate or less severe and remains reasonably well controlled, but others experience chronic disabling pain, inflammation, stiffness, chronic fatigue and reduced joint function and impaired mobility. Chronic fatigue, in particular, is an invisible symptom of the disease that can severely impact upon a person's quality of life and ability to work and requires better understanding and management.

## 3.2 Definition

There is no universally agreed definition of fatigue in RA within the medical literature<sup>1</sup>. However, chronic fatigue has been defined as ‘unpleasant, unusual, abnormal or excessive whole-body tiredness, disproportionate to or unrelated to activity or exertion and present for more than one month. Chronic fatigue is constant or recurrent, it is not dispelled easily by sleep or rest and it can have a profound negative impact on the person's quality of life’<sup>2</sup>.

Those who experience chronic fatigue, report that it is as different from tiredness as flu is from a cold and can come on without warning<sup>3</sup>. Fatigue can affect people with any type of arthritis, but it is more common in people with forms of inflammatory arthritis, such as RA<sup>4</sup>.

## 3.3 Causes

The causes of chronic fatigue in RA are complex and not well understood, with a number of possible factors associated with its occurrence and severity. Pain, stress, depression, inflammation, and disability are all factors that may contribute in varying degrees at different times<sup>5</sup>.

Fatigue is more common in women than men and can be more severe in the early stages of RA<sup>6</sup>. Younger women with multiple daily roles may be especially vulnerable to the negative impact of fatigue<sup>7</sup>.

Inflammation may cause chronic fatigue. This may be due to the presence of cytokine chemicals found in inflamed tissues<sup>8</sup>. However, the correlation with chronic fatigue is not consistent<sup>9</sup> and the association with disease activity is deemed to be secondary to pain<sup>10</sup>.

Anaemia can affect energy levels and it is estimated prevalence of mild anaemia in RA patients ranges between 33% and 60%. Some research shows a link between resolving anaemia and associated improvements in symptoms<sup>11</sup>, while other research finds that fatigue is independent of anaemia<sup>12</sup> with no links between low levels of haemoglobin and the onset of chronic fatigue<sup>13</sup>.

Low mood or depression due to uncertainty about the future can reduce energy and promote fatigue<sup>14</sup>. Fatigue itself is also a symptom of depression, which is

more common in people with RA than the general population<sup>15</sup>. Studies indicate that between 8% and 46% of people with RA have depressive symptoms<sup>16</sup>. RA patients are also twice as likely to suffer from depression as the general population<sup>17</sup> and those diagnosed with RA and depression may also have suicidal ideation<sup>18</sup>. Other aspects of cognitive and emotional functioning may affect chronic fatigue such as perceptions of self-efficacy<sup>19</sup>.

Pain is a major symptom that can wear people with RA down and prevent them from sleeping properly. Sleep may also be disturbed due to anxiety or stress, which can then cause fatigue. Research has found that 60% of people with RA have their sleep regularly disturbed<sup>20</sup>.

Pain can also cause chronic fatigue in other ways. For example, when people with RA are unable to exercise, or do not exercise because they are anxious about exercising for fear of making their disease worse, their muscles can become weak. As a consequence, just getting around requires extra effort, which can increase fatigue<sup>21</sup>.

It has been suggested that the continued release of the hormone adrenaline during periods of prolonged stress, due to constant pain or anxiety about the future, may also be a cause of fatigue<sup>22</sup>. Social and environmental aspects, such as interpersonal events and social support may also influence levels of chronic fatigue<sup>23</sup>.

Persistent, severe fatigue has been linked to general health and disability<sup>24</sup>. However, the complex inter-relationship between all of these factors means that chronic RA fatigue is likely to be caused by a combination of them<sup>25</sup>.

### 3.4 Impacts on quality of life

Fatigue is a major concern for RA patients<sup>26</sup> and is regarded as a physical and cognitive symptom that is overwhelming, uncontrollable, unpredictable, unearned and affects every aspect of life<sup>27</sup>. Beside pain, fatigue has been described as the most prominent symptom in RA, with a greater impact on daily life than pain<sup>28</sup>.

Different definitions and instruments have been used to try and measure chronic fatigue. This has led to large ranges in estimated prevalence of between 42% and 80%<sup>29</sup>. One study reported effects for up to 98% of RA patients<sup>30</sup> and research also suggests the greatest negative impact from fatigue may be found in younger persons<sup>31</sup>.

Chronic fatigue may occur at any time of the day, including when people with RA wake up. This causes them to feel unrefreshed<sup>32</sup> and may give rise to the generally unavoidable need to sleep during the day<sup>33</sup>.

However, chronic fatigue may also occur when people with RA are physically active or concentrating a lot or without a clear cause or warning. Duration may last anywhere from an hour to the whole day and can continue over several days or weeks at a time<sup>34</sup>.

In terms of severity, 40% of RA patients who experience fatigue may experience persistent severe fatigue. This is a level comparable to patients with Chronic Fatigue Syndrome<sup>35</sup>. Even when levels of inflammation are low, many RA patients may continue to report moderate to high levels of fatigue<sup>36</sup>. Severe fatigue is not resolved spontaneously in RA patients<sup>37</sup>.



“Mental fatigue, also referred to as ‘brain fog’, may occur and affect the ability of a person with RA to think clearly and lose their concentration or motivation.”

People with RA report that chronic fatigue has significant, wide-ranging impact. These include feeling unable to achieve optimal physical and mental function, a lack of enthusiasm, having to modify expectations and adopt unwelcome, dependant roles in their lives<sup>38</sup> and being prevented from doing planned activities and everyday tasks<sup>39</sup>. People with RA also report problems looking after their children<sup>40</sup>.

Mental fatigue, also referred to as ‘brain fog’, may occur and affect the ability of a person with RA to think clearly and lose their concentration or motivation. Emotional fatigue is another impact which can make people irritable, down or tearful<sup>41</sup>, impatient and frustrated, and can cause relationships to become strained<sup>42</sup>.

Chronic fatigue has also been identified as one of the symptoms in RA flares, with flare fatigue tending to be of a higher intensity. Some RA patients have also reported that fatigue can signal early onset of a flare<sup>43</sup>.

Occurrence of chronic fatigue is also associated with physical effects, such as ocular and oral dryness and morning stiffness<sup>44</sup>.

Finally, the way patients cope with fatigue has been demonstrated to affect their quality of life<sup>45</sup>.

### 3.5 Impacts on work

A systematic review of research into sick leave in inflammatory arthritis patients found that recorded rates varied from 3.7% in the past 4 days to 84% during the past 2.5 years. Total duration of sick leave ranged from 0.1 to 11 days over the course of 1 month. Studies have found that between 17% and 88% of inflammatory arthritis patients experience workplace productivity loss<sup>46</sup>.

RA affects work outcomes in several ways. People may miss days from work (absenteeism), endure reduced work productivity (presenteeism), face the prospect of increased job turnover (stopping work or switching to less demanding jobs), as well as additional costs associated with accommodating the disease at work<sup>47</sup>. Around three quarters of people with RA are first diagnosed when of working age. The additional cost of RA to the UK economy, including sick leave and work-related disability, is estimated to be £3.8 to £4.8 billion a year<sup>48</sup>.

Work disability begins quickly after diagnosis and increases steadily<sup>49</sup>, with one study suggesting that in the first four years of the disease only 10% of RA patients are completely free of any changes with respect to the performance of their occupational roles<sup>50</sup>. Furthermore, around two-thirds of people with RA who are employed have experienced work loss as a result of their disease in the previous 12 months<sup>51</sup>.

Overall, a quarter of people with RA give up work due to their disease within 1 year of diagnosis and over half stop within 6 years<sup>52</sup>. Between 50 and 90% stop working before the age of 65<sup>53</sup>. A systematic review of studies of productivity loss due to RA found that 66% of employees with RA reported work loss due to the disease in the past year, with a median duration of 39 days<sup>54</sup>.

People in employment with RA target staying in work, but once they lose their job and have adapted to their loss, the motivation to work is lost<sup>55</sup>. Having a job may help people with RA to cope with their disease and a study found that the incidence of depression is higher amongst people with RA who are not in work<sup>56</sup>. There is also some evidence that women continue working with higher scores of disease activity and functional disability compared with men<sup>57</sup>.

Return to work initiatives for RA patients lack success and it has been recommended that self-reported presenteeism measures are used to screen for risk of work disability, while they are still in work<sup>58</sup>.

Radiographic progression is predictive of ability to retain or gain employment<sup>59</sup>. Functional disability and job type at the start of the disease are also predictors of future work disability. A Dutch study found that 37% of people with RA in employment had changed their working conditions: reduced working hours (46%), reduced pacing of work (42%) and help from colleagues (49%) were the most widely reported alterations<sup>60</sup>.

Chronic fatigue causes changes in cognitive ability, ability to act, and overall activity patterns due to the increased need to rest or sleep, which makes it difficult not to affect work capability<sup>61</sup>. Chronic fatigue is the third largest factor to affect ability to work among employed respondents and the second largest factor among those that were unemployed<sup>62</sup>.

A Scottish study suggests chronic fatigue may be an even more important factor affecting ability to of people with RA to work, with 81.1% of respondents in employment citing it as a major barrier, compared to 79.6% of unemployed respondents. In the same survey, 18.5% of respondents said they changed occupation either due to the physical limitations of the disease, or fatigue<sup>63</sup>.

For those unable to stay in work, many will choose to claim the Employment and Support Allowance (ESA). Eligibility to claim ESA is principally determined via completion of the Work Capability Assessment (WCA), which attempts to classify the extent that a claimant's disease or disability affects their ability to work.

The WCA focuses on ability to carry out activities. Every activity has descriptors which carry a score and there are ten physical activities and seven cognitive activities. The assessment takes into account any aid used or reasonably expected to be used. Whilst the current guidance for assessors says they should take into account exhaustion when completing tasks and the descriptors for the activities reference exhaustion, none of the descriptors for the activities explicitly refer to the role of chronic fatigue<sup>64</sup>.

Of people with RA making a new claim for ESA, between 2008-2011, 50% were placed in the Work-Related Activity Group and deemed able to eventually return to work whilst 16% (880) were placed into the Support Group and 34% (1,950) were found fit for work<sup>65</sup>.

Only 22% of people with RA who responded to a Disability Benefits Consortium (DBC) Big Benefits Survey in 2013 felt the assessor knew about their condition. Furthermore, almost two-thirds of respondents (61%) thought the WCA was not long enough for the assessor to learn about all the symptoms and aspects of their RA and its impact on their capability to work<sup>66</sup>.

The DBC survey showed that, of the people with RA who had seen their Atos medical report, 70% thought it was not an accurate reflection and only 21% of those with RA who had undertaken a WCA thought it took account of chronic pain and fatigue<sup>67</sup>.

Thus, to improve work outcomes for people with RA the evidence suggests that it is better to keep patients in the workforce than to allow patients to become work disabled. However, in cases where people with RA do become work disabled, it has been recommended that further reform of the WCA descriptors takes place to take account of fluctuations, including the issue of fatigue<sup>68</sup>. In 2011, several patient

“The main medical guidelines which cover the management and treatment of RA around the UK contain only passing references to the effective management of chronic fatigue.”

organisations, representing people with other fluctuating conditions, publically called for the introduction of an additional descriptor to cover fatigue and pain, where it is a prominent recognised symptom of an existing disorder or condition<sup>69</sup>.

### 3.6 Management of chronic fatigue

The main medical guidelines which cover the management and treatment of RA around the UK contain only passing references to the effective management of chronic fatigue.

The National Institute for Health and Care Excellence (NICE) published Clinical Guideline 79 on the management of rheumatoid arthritis in adults in 2009. This describes best practice in treatment and management of the disease and is applicable within England, Wales and Northern Ireland<sup>70</sup>. The guideline recommends that people with RA should have the opportunity for periodic assessments of the effect of the disease on their lives, including fatigue, and help to manage the condition<sup>71</sup>.

Meanwhile, the more recently published NICE Quality Standard 33 on rheumatoid arthritis, which is applicable to England only<sup>72</sup>, states it is important to improve patients’ understanding of RA and its management through educational activities and self-management programmes to enable them to better manage aspects of their disease, including fatigue<sup>73</sup>.

In Scotland, SIGN Guideline 123 on the management of RA, which serves as the equivalent to NICE Clinical Guideline 79, does not specifically mention chronic fatigue, although it makes reference to the importance of multi-disciplinary expertise, such as physiotherapists. The document also makes a brief reference to the potential role that patient-led self management education programmes can play in helping RA patients with problem solving<sup>74</sup>.

At the same time, research suggests that most patients do not discuss fatigue with their healthcare professionals because they feel it is ignored<sup>75</sup>, dismissed or they simply accept fatigue as part of the disease<sup>76</sup>. Indeed, RA patients report feeling they are on a ‘conveyor belt’ of treatment, or that their healthcare professional sees their RA as a condition to be treated, instead of seeing the patient as ‘a person with RA’<sup>77</sup>.

### 3.7 Measurement of chronic fatigue

The importance of measuring chronic fatigue in clinical outcomes is increasing. Fatigue is not always included in common RA disease activity indices, like the Disease Activity Score-28. However, results from an Outcome Measures in Rheumatology Clinical Trials RA flare group initiative found that fatigue was an important domain for patients with established disease. The American Congress of Rheumatology and the European League Against Rheumatism also recognise fatigue as an important domain for inclusion in clinical trials and fatigue is also now included within the Rheumatoid Arthritis Impact of Disease score<sup>78</sup>.

Several scales have been developed and applied to the measurement of chronic fatigue within RA. These include the Functional Assessment of Chronic Illness Therapy–Fatigue (FACIT-F), Multidimensional Assessment of Fatigue (MAF), Profile of Mood States, and Short Form 36 (SF-36) vitality subscale<sup>79</sup>.

The Bristol Rheumatoid Arthritis Fatigue Multi-Dimensional Questionnaire (BRAFM-DQ) has recently been developed specifically for RA. It aims to capture physical, psychological and social aspects of fatigue. Three accompanying scales also assess severity, effect and coping. Evidence supports its validity and it has been suggested



the scale could be used to develop individually-tailored fatigue management programmes<sup>80</sup>.

Despite advances in measurement of chronic fatigue, certain additional challenges still remain. For example, a study of UK Punjabi women found that their experience and the cultural meaning of fatigue is different, which may be due to differences in the way symptoms are interpreted as well as how they experience them<sup>81</sup>.

### 3.8 Treatment of chronic fatigue

A number of interventions may help to manage the manifestation of chronic fatigue in RA, but require further validation and need to be refined. There is also some evidence to suggest that levels of fatigue decrease when the disease is brought under control<sup>82</sup>.

Studies on the effectiveness of DMARD and anti-TNF therapy demonstrate evidence that they can make significant improvements to RA fatigue<sup>83</sup>.

Combination therapy is associated with more positive work outcomes than methotrexate monotherapy, including less absenteeism, less presenteeism, and greater likelihood of gaining or retaining employment<sup>84</sup>. Occupational therapy also improves work retention and reduces work-related disability in employed RA patients<sup>85</sup>.

Psychological interventions have also been proven to work. For example, a randomised controlled study of cognitive-behavioural therapy showed its ability to generate significant improvements in levels of fatigue for RA patients<sup>86</sup>. Fatigue self-management in RA, delivered by an OT and psychologist, improves fatigue impact, coping and perceived severity, and well-being<sup>87</sup>.

Additional research into talking therapies for arthritis-related fatigue has shown it can also help reduce the impact. Testing is now being undertaken to see if these can be delivered by the rheumatology team rather than a psychologist<sup>88</sup>.

A further randomised controlled study on non-pharmacological interventions on home aerobic training also demonstrated improvements in levels of fatigue<sup>89</sup>.

These results have been supported by a Cochrane Review, which concluded that physical activity and psychosocial interventions provide benefit in relation to self-reported fatigue in adults with RA, although there is insufficient evidence about the effectiveness of other non-pharmacological interventions<sup>90</sup>.

### 3.9 Public awareness

Research shows there is a 'window of opportunity' for RA patients. Those diagnosed and started on optimal treatment using disease-modifying anti-rheumatic drugs (DMARDs) within twelve weeks of symptom onset stand a much better chance of achieving remission or a low disease activity state<sup>91</sup>. Even delays of 8–9 months in starting DMARD therapy significantly affect disease outcomes years afterwards<sup>92</sup>, even if more potent treatment strategies are subsequently applied<sup>93</sup>.

The failure of RA patients to consult their GP is one of the principle reasons for delays in seeing a rheumatologist in the UK in comparison to other health systems<sup>94</sup>. Research for the National Audit Office found that 15% of RA patients identified delaying seeking medical help as one of the main factors that impeded prompt diagnosis<sup>95</sup>.

Evidence about the impact of poor public awareness has led a number of organisations to recommend that further action is taken to invest in the creation

“Chronic fatigue is inadequately addressed within the major government strategies for musculoskeletal and long term conditions across England, Scotland, Wales and Northern Ireland.”

of public awareness campaigns. These include the National Audit Office, the House of Commons Public Accounts Committee, the Scottish Public Health Network, the Arthritis and Musculoskeletal Alliance and the National Rheumatoid Arthritis Society<sup>96</sup>. Currently, Scotland is the only country to invest in the creation of a public awareness leaflet<sup>97</sup>.

Chronic fatigue is one of a number of early signs and symptoms of RA; the others being joint pain, joint swelling, stiffness, fever, and often weight loss. All of these symptoms, including fatigue, are not specific to RA and can be attributed to other medical conditions. This makes it difficult for the public to identify these symptoms as part of RA<sup>98</sup>.

A national survey of the attitudes of the British public towards RA in 2013 found that extreme fatigue was the least well-known disease symptom. 31% of survey respondents identified it as a symptom. Among survey respondents who had claimed to have seen public information about RA the figure was 10 percentage points higher at 45%<sup>99</sup>.

The same survey found that just 23% of the 16-34 age bracket recognised extreme fatigue as a symptom of RA compared with 45% in the 55-64 year old bracket. Scottish respondents were also more likely to recognise extreme fatigue as a symptom of RA (41%) compared to those in England (34%) and Wales (35%). White respondents (36%) were also more aware of extreme fatigue as a symptom, in comparison to BME respondents (22%)<sup>100</sup>.

### 3.10 Government policies

Chronic fatigue is inadequately addressed within the major government strategies for musculoskeletal and long term conditions across England, Scotland, Wales and Northern Ireland.

The topic of chronic fatigue itself is rarely mentioned within these strategies. In one of only two direct policy references, the *Musculoskeletal Services Framework* in England, published in 2006, called for access to adequate education and support to help patients manage exacerbations of fatigue<sup>101</sup>. In Wales, the *Arthritis and Chronic Musculoskeletal Services Directive*, a document that sets out the vision for RA services, which was published in 2007, also notes the negative impact fatigue has on physical activity and its links to comorbidities (heart disease, diabetes and obesity) as well as the need for service planners and commissioners to be aware of it as a hidden impairment<sup>102</sup>.

Furthermore, important cross-cutting themes mentioned in the medical guidelines for the treatment of RA - access to multi-disciplinary expertise to ensure effective treatment; provision of holistic annual reviews to discuss outcomes; and access to self-management support to encourage preventative action and minimise effects – are echoed to varying degrees in government strategies for musculoskeletal and long term conditions in the UK.

The importance of access to multi-disciplinary expertise is well recognised in policies across UK policies. In England and Wales, where musculoskeletal strategies exist, these strategies set out a vision for integrated multi-disciplinary working across the health economy<sup>103</sup> and cite evidence that managed care coordinated by a range of disciplines can provide positive outcomes and help to reduce demands on secondary care services<sup>104</sup>. Of particular note, in Wales the *Arthritis and Chronic Musculoskeletal Conditions Directive* introduced a commitment on commissioners to ensure timely access to healthcare professionals through specialist integrated multi-disciplinary teams<sup>105</sup>. This was then followed by the *Designed to Improve Health* and the *Management of Chronic Conditions in Wales: Service Improvement*

*Plan 2008-11*, published in 2008, which also prioritised better anticipation of individual needs and targeted delivery of a coordinated service for people with chronic conditions<sup>106</sup>.

Access to multi disciplinary teams is also established in Scotland via the *Delivering for Health* strategy, published in 2005, which committed the Scottish Government to delivering integrated care involving multi-disciplinary teams<sup>107</sup>.

Meanwhile, Northern Ireland's *Quality 2020 - A 10 Year Quality Strategy for Health and Social Care in Northern Ireland*<sup>108</sup> and the draft *Long Term Conditions Policy Framework for Adults in Northern Ireland*, both published in 2011, promote holistic needs assessment for people with long term conditions<sup>109</sup>.

Visions for supported self-management are also quite well, though not consistently, established throughout the UK. Long term conditions strategies in both Scotland and England refer to self-management and acknowledge the role it can play in improving clinical outcomes and quality of life.

Notably, Scotland has a particularly well defined and established vision of self-management. Not only did the Scottish Government's *Long Term Conditions Strategy* commit to ensuring people are sign-posted to the type of support and information they need, including a more outcome-focused approach to planning and reviewing their individual situation<sup>110</sup>, but significantly, a strategy for self-management was also developed. *Gaun Yersel: The Self Management Strategy for Long Term Conditions* seeks to ensure that people with long term conditions are given access to support to manage their condition, including information leaflets and self management courses<sup>111</sup>. The Scottish Government has also provided funding for a dedicated Self-Management Fund (now called the Self Management IMPACT Fund) to support expansion and innovation within this domain<sup>112</sup>.

Within England, The Coalition Government confirmed its commitment to self-management through the *Equity and Excellence: Liberating the NHS* White Paper, which specified that a self-management strand would be developed within the Quality, Innovation, Productivity and Prevention (QIPP) transformational programme<sup>113</sup>. However, this has not been consistently embedded across policy frameworks in England. For example, while the NHS Mandate to NHS England 2014-2015 and the NHS Outcomes Framework 2014 address 'Enhancing the quality of life for people with long term conditions', in the case of the NHS Mandate it does not refer directly to the role of self-management<sup>114</sup>. Indicators are however included in the NHS Outcomes Framework 2014 which commit to ensuring everybody has access to support and information to help them manage their care needs<sup>115</sup>. The CCG Outcomes Indicator Set, which sets out comparative information about the quality of health services commissioned by Clinical Commissioning Groups, also contains an indicator that aims to ensure that people with long term conditions feel supported to manage their condition<sup>116</sup>.

In Wales, *Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century* set out a vision to help individuals become expert patients and take on a high degree of control over their treatment remodel care pathways to provide better access to self-management training<sup>117</sup>. The *Welsh integrated model and framework for the management of Chronic Conditions* also sets out that encouraging self management is essential<sup>118</sup>. The *Service Improvement Plan 2008-2011* for this Model includes the objective to 'increase self-management, independence, and the participation of people with chronic conditions and their carers'<sup>119</sup>.

Latterly, in Northern Ireland, the Department of Health, Social Science and Public Safety has published *Living with Long Term Conditions: A Policy Framework*, which



“I find the fatigue much harder to deal with than the pain. And the pain is much easier to fix than the fatigue.”

includes a commitment to supporting self-management that provides people with long term conditions with the knowledge and skills they need to manage their own condition confidently and make daily decisions which maintain or enhance their health and well-being and clinical, emotional and social outcomes<sup>120</sup>.

Compared to both access to multi disciplinary teams and supported self management, the role of the annual reviews has been less well described within government strategies across the UK.

In Scotland, the *Long Term Conditions Action Plan* contained a commitment to developing shared approaches to setting goals and problem solving, and signposting people to the type of support and information they need, including a more outcome-focused approach to planning and reviewing their individual situation<sup>121</sup>.

Meanwhile in Wales, the *Designed to Improve Health and the Management of Chronic Conditions in Wales: Service Improvement Plan 2008-11*, flags the importance of better anticipating the needs of individuals<sup>122</sup>.

Elsewhere, the *Quality 2020 - A 10 Year Quality Strategy for Health and Social Care in Northern Ireland* and the *Long Term Conditions Policy Framework for Adults in Northern Ireland*, have sought to promote holistic needs assessment for people with long term conditions<sup>123</sup>.

In England, whilst care planning is mentioned within the NHS Mandate, there are no specific references to the role of annual reviews<sup>124</sup>.

### 3.11 Implementation

Measuring current levels of compliance with best practice is difficult to do, but an array of different evidence suggests that the medical guidelines and public policy frameworks produced, which aspire to deliver good quality care for people with RA (and therefore address the management of chronic fatigue), are not being fully implemented across the UK.

The importance of annual reviews has been highlighted during discussions about medical guidelines (see section 3.6) and public policy (see section 3.10), but evidence from a National Audit Office (NAO) census in England conducted in January 2009 found that only 63% of acute trusts offered RA patients an annual review. This finding was itself thrown into doubt when NRAS conducted follow-up surveys with RA patients and healthcare professionals in 2010 and found that 55% of patient respondents said they had not had an annual review. 57% of consultant rheumatologists also said they had seen no changes in the past year in access to holistic annual review<sup>126</sup>.

The significance of getting access to multi-disciplinary expertise has also been discussed in relation to medical guidelines (see section 3.6) and public policy (see section 3.10). Once again, evidence of implementation is mixed. In 2010, the House of Commons Public Accounts Committee concluded there was inconsistent provision of multi-disciplinary services by former Primary Care Trusts in England for RA patients<sup>127</sup>. The Scottish Public Health Network's Health Care Needs Assessment on RA, published in 2012, also found that the provision of multi-disciplinary teams was patchy and that most units did not have all professions attached to their unit<sup>128</sup>.

The situation is further illustrated via challenges to accessing physiotherapy. Physical activity in the treatment of RA fatigue is beneficial (see section 3.8), but a census of acute trusts in England in 2008 concluded that fewer than 75% of trusts provided access to a physiotherapist for RA<sup>129</sup>. In the same year, the Clinical Audit of Care in Rheumatoid Arthritis in Scotland also concluded there were significant

variations in the availability of physiotherapy services in different rheumatology units<sup>130</sup>. A survey conducted by Medix in 2009, commissioned by the NAO, also found that almost a quarter of GPs in England did not adopt best practice and give all patients with RA routine access to specialist physiotherapy with periodic review<sup>131</sup>.

A similar picture is revealed for access to psychological support for RA patients. Although psychological treatments can also help to treat chronic fatigue (see section 3.8), an NAO report in 2009 found that just 14% of acute trusts provided access to psychological services for RA patients<sup>132</sup>. The House of Commons Public Accounts Committee in 2010 also expressed concern about restricted access to psychological services<sup>133</sup>.

In respect to other aspects of holistic care, the 2009 NAO report found that half of the 147 acute trusts that responded to their census said they provided care plans for RA patients, although 30% did not provide any. The NAO recommended that all people with RA should be offered a care plan that includes a holistic assessment of the overall well-being of the individual and support them to return to or remain in work<sup>134</sup>.

Information about implementation of self-management for RA patients is limited. The 2009 NAO report found that almost half of GPs thought the NHS was not effective at providing RA patients with self-management information and there was a lack of coordination in the way advice about self-management was provided to patients. The report also found that only 29% of Primary Care Trusts commissioned services covering self-management for people with RA<sup>135</sup>. In Scotland, research published by the Arthritis and Musculoskeletal Alliance in 2011 found that the majority of NHS Boards in Scotland provided information to MSK patients to help them self-care, but Board activity varied significantly, from simple leaflets to online resources and portals. ARMA therefore called for long term conditions to be better mapped to understand the resources needed to treat people with musculoskeletal conditions. In comparison, the Welsh Audit Office found that support for patient education and self-care in Wales had improved since 2008, but the uptake and completion of these programmes was still too low – falling short of the Welsh Government’s 2009 target to get 1% of those with a chronic condition through these programmes within three to four years. The WAO report also said that all health boards were implementing a national generic self-management education programme for people with a long-term condition and that the number of participants completing a self-management education programme increased by 53% between 2011 and 2013<sup>136</sup>.

Self Management UK (SMUK), the largest provider of self-management programmes in the UK, runs a Rheumatoid Arthritis Self Management Programme in conjunction with NRAS. The 6-week course includes sections on management of pain and fatigue. As of November 2013, SMUK had run a total of 5,000 courses for 70,000 participants with long term conditions<sup>137</sup> approximately 100,000 of these were for its Chronic Disease Management Programme. No information is publicly available at the moment about the number of people who have attended the RA Self Management Programme, or other similar programmes.

### 3.12 Calls for action

Despite evidence of poor measurement and management of chronic fatigue highlighted in the literature review, there have been no notable calls to action from organisations. Instead, the main calls for action have come from patients.

A quantitative study of female patients carried out in Ireland found that fatigue was the top health status measure patients wanted prioritised for improvement<sup>138</sup>.

“I have felt very intimidated and upset by having to justify to my managers why life is tiring.”

Research indicates that gender influences the prioritisation of outcomes, with women selecting fatigue more frequently than men<sup>139</sup>.

An additional qualitative study involving focus groups at five UK clinical centres found that treatment of fatigue was consistently mentioned as an important outcome<sup>140</sup>.

### 3.13 Survey and its methodology

The questions in the survey were developed by NRAS in order to explore the range of impacts of chronic fatigue on RA patients and to support and provide insight for Rheumatoid Arthritis Awareness Week in June 2014.

The questions were developed from the literature, issues raised by NRAS members during a focus group on RA fatigue, and in response to answers received from the British public about public awareness of RA.

To explore issues around the impact on quality of life and work and to facilitate comparison with existing research on RA fatigue, a number of validated questionnaires were also used:

- Bristol Rheumatoid Arthritis Fatigue Multi-Dimensional Questionnaire (BRAFM-DQ)
- Bristol Rheumatoid Arthritis Fatigue – Numerical Rating Scales (BRAFM-NRS)
- Work Productivity and Activity Impairment Questionnaire (WPAI); and
- Work Activity Limitations Scale (WALS)

An online survey was selected as the preferred method of data collection to be distributed to NRAS members and non-members with RA. It was designed in conjunction with three university researchers with expertise in chronic fatigue and work.

The survey was subsequently reviewed by a panel of NRAS members with RA. Questions and design were then subsequently amended to take account of these comments.

A series of closed questions were used in order to produce statistical evidence. In addition, a number of open questions were included to give respondents the scope to express their own opinions.

NRAS sent out 5,212 electronic questionnaires to NRAS members with RA and non-members with RA who had email addresses in April 2014. It was also sent out to 1,237 healthcare professionals, as part of a monthly e-newsletter, to encourage them to ask their patients to complete the survey.

A separate email was circulated to healthcare professionals in Wales and Scotland on 02 May 2014 to encourage their patients to complete the survey. A final reminder for the questionnaire was sent out on 13 May 2014 to NRAS members via an e-news bulletin.

The questionnaire was also publicised via email and NRAS social media platforms, Twitter, Facebook and HealthUnlocked, and through health sector newsletters to attract non-members to respond.

2,065 complete responses were returned (where response means responded to all questions which the survey logic would allow).

Of these, 36 respondents did not satisfy the conditionality of being over 18, living in the UK and having been diagnosed with RA and answered 'no' to the covering survey question and were thus precluded from answering any further questions.

2,029 of the complete responses satisfied this conditionality and so progressed to answering the survey. Of these, 75 responded that they had 'never had fatigue' to Q8 in the survey and so were prevented by the survey logic from answering further questions. This means a total 1,954 respondents completed the survey all the way to the end.

It should also be noted that 814 respondents indicated they were currently in employment and so this was the sample size for the section of the survey on employment (Q22-34).

Data were subsequently analysed in Microsoft Excel Starter 2010 and percentages were calculated accordingly. A selection of quotations have been used in the report for qualitative illustration of the statistical data.



# 4 Key findings

“I feel totally exhausted; like a tap suddenly opens all my energy (what little I have) disappears in a instance. It can last hours, days, weeks or months.”

## 4.1 The survey respondents

All of the respondents who took the survey had been diagnosed with RA\*. 2,745 respondents began the survey, and 2,029 respondents completed the survey. For the purposes of this report, NRAS analysed only completed responses.

57% of the respondents (n=1,157) said they, or a member of their family, are a member of NRAS. The large number of respondents who were non-members enhances the degree to which the survey findings can be generalised to the RA population in the UK.

### 4.1.1 Respondents' age

Of the 2029 respondents, the largest age category was 55-64 year olds (30%). The next biggest age category was the 45-54 year olds (27%) followed by 65 years and over (20%).

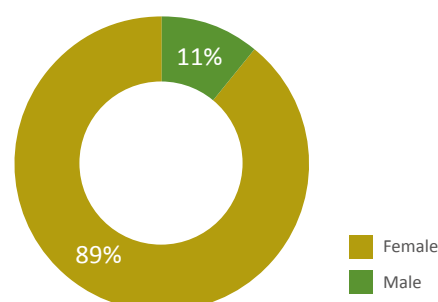
Amongst respondents who had been diagnosed for less than a year, the largest age category was 45-54 year olds (29%), followed by 35-44 year olds (28%) and 55-64 year olds (21%). This reflects the distribution we would expect to see within the general population. Although the disease can occur at any age, onset is usually between the ages of 30 to 55<sup>141</sup>.

	All respondents	Diagnosed for less than 1 year
Age	Response (%)	Response (%)
18-24	1%	1%
25-34	6%	12%
35-44	16%	28%
45-54	27%	29%
55-64	30%	21%
65 and over	20%	9%

### 4.1.2 Respondents' gender

89% of respondents were female whilst 11% were male. The proportion of women is higher in this sample than we would expect to see in the RA population as a whole, in which RA is estimated to affect around three times more women than men<sup>142</sup>. This gender bias is a recognised phenomenon in surveys conducted by patient organisations, where group membership, regardless of medical condition, tends to be dominated by women<sup>143</sup>.

Respondents' gender



\* Respondents also had to state they lived in the UK and were aged 18 or over to continue the survey.

### 4.1.3 Respondents' ethnicity

The overwhelming majority of respondents identified themselves as White: British (93%), an additional 2% identified themselves as White: Irish and 2% as White: Other. 3% identified themselves as coming from a BME or mixed race background. The proportion of white respondents is higher than the UK population, which according to 2011 Census data, stands at 86%<sup>144</sup>.

Ethnicity	Response (%)	Ethnicity	Response (%)
White: British	93%	Asian or Asian British: Pakistani	0%
White: Irish	2%	Asian or Asian British: Bangladeshi	0%
Other White background	2%	Other Asian background	0%
Mixed: White and Black Caribbean	0%	Black or Black British: Caribbean	1%
Mixed: White and Black African	0%	Black or Black British: African	0%
Mixed: White and Asian	0%	Other Black background	0%
Other Mixed background	0%	Chinese	0%
Asian or Asian British: Indian	1%	Other ethnic group	0%

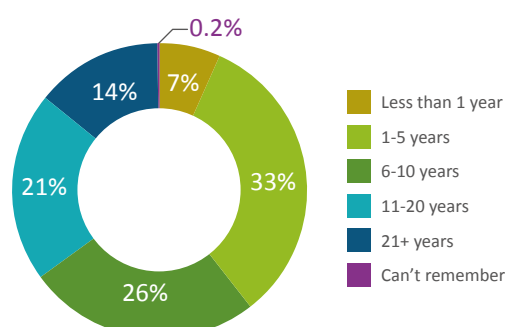
### 4.1.4 Where respondents live

NRAS received 1758 completed responses from people in England, with 8% (155) received from Scotland, 5% (91) from Wales and 1% (25) from Northern Ireland. Within England, the majority of responses came from the South East, which accounted for 24% of all completed responses.

### 4.1.5 Length of time since RA diagnosis

The largest category of respondents were those diagnosed with RA for 1-5 years (33%), followed by those diagnosed for 6-10 years (26%) and 11-20 years (21%). Much smaller proportions of respondents were diagnosed with RA for more than 21 years (14%), or for less than 1 year (7%).

Length of time since RA diagnosis



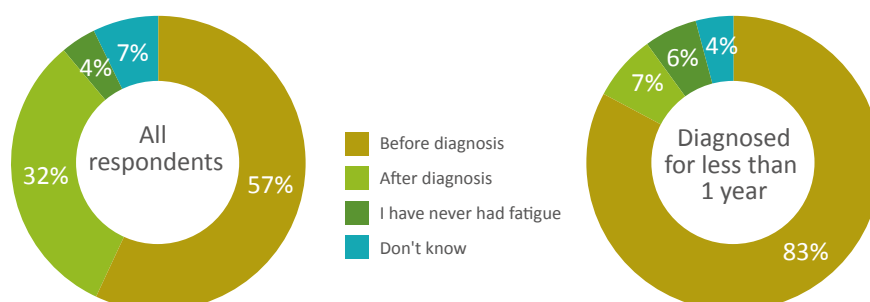
## 4.2 About your fatigue

### 4.2.1 Onset

89% of respondents said they suffered from fatigue with only 4% stating they never had fatigue. The prevalence reported by respondents was higher than the range of estimated prevalence in most other research on RA fatigue (42%-80%)<sup>145</sup>, although lower than the highest recorded levels of 98%.

The majority of respondents (57%) said their fatigue first appeared before diagnosis and only 32% said it appeared after diagnosis. Amongst the respondents who said they had been diagnosed with RA for less than 1 year, 83% reported that fatigue first appeared before diagnosis and only 7% said that it appeared subsequently.

Symptom occurrence



### 4.2.2 Frequency

The frequency of fatigue reported amongst respondents was very high: 84% said they experienced it for 3 days or more during the last 7 days, including 41% who said they experienced fatigue every day. The percentage that experienced it every day rose to 47% among those diagnosed with RA more than 21 years ago but was only 37% amongst those diagnosed for less than 1 year.

Episodes of fatigue occurred slightly more frequently amongst respondents not currently in employment versus those in employment. 81% of those in employment said they experienced fatigue 3 days or more in the past 7 days, including 37% who experienced it every day. By comparison, among those not in employment, 86% said they experienced it 3 days or more and 43% experienced it every day.

### 4.2.3 Duration

In addition to the majority of respondents who said they experienced fatigue on most days, a high number also said fatigue affected them for a significant portion of the day. 55% of respondents said their fatigue lasted for several hours, and an additional 39% said that fatigue lasted all day.

### 4.2.4 Level and impact

When asked about the level of their fatigue during the last 7 days, 98% of respondents reported some level of occurrence. 46% said they experienced a high level of fatigue, while 33% experienced a medium level and 8% said they were totally exhausted.

Of those respondents currently in employment, 5% rated their level of fatigue as totally exhausting, compared to 10% of respondents not currently in employment.

When respondents were asked to report the impact of their fatigue over the past 7 days, 13% said it had a very high level of impact on them and a further 41% also reported a significant level of impact.

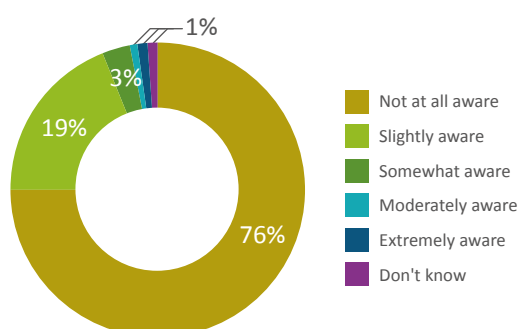
Respondents not currently in employment reported that fatigue had a higher impact on them over the past 7 days (15%) compared to employed respondents (11%).

## 4.3 Public awareness

### 4.3.1 Symptoms

Respondents felt RA fatigue was poorly understood by the public. 76% of respondents said the public was not at all aware that chronic fatigue was a symptom of RA, while 19% said the public was slightly aware and only 3% said the public was somewhat aware.

Public awareness of chronic fatigue as a symptom of RA



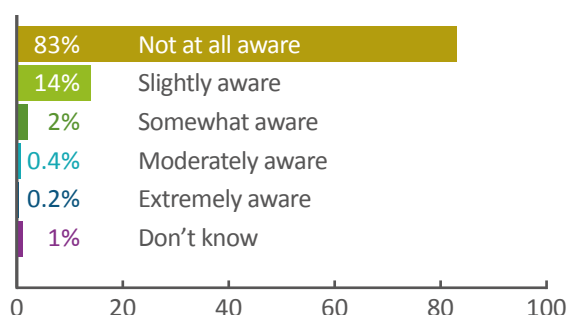
Overall, chronic fatigue was ranked as the least understood symptom by respondents, closely followed by flu-like symptoms. However, amongst respondents diagnosed with RA for less than 1 year, chronic fatigue narrowly came second to flu-like symptoms as the least understood symptom. In total, 45% of respondents ranked chronic fatigue as the least understood symptom of RA.

Public understanding of RA symptoms	Average rating (Ranked 1-5. 5 = Least understood)
Joint swelling	1.93
Chronic pain	2.32
Morning stiffness lasting 30 minutes or longer	2.74
Flu-like symptoms	4
Chronic fatigue	4.01

### 4.3.2 Impact

83% of respondents felt the public was not at all aware of the impact of fatigue on RA patients and a further 14% said they were only slightly aware.

Public awareness of the impact of chronic fatigue on people with RA





“I feel like I have limbs of lead, and even completing the smallest of tasks leaves me totally drained. It also leaves me feeling tired emotionally.”

These results are in line with previous NRAS research, which found that chronic fatigue was the least understood symptom of RA by the British public<sup>146</sup>.

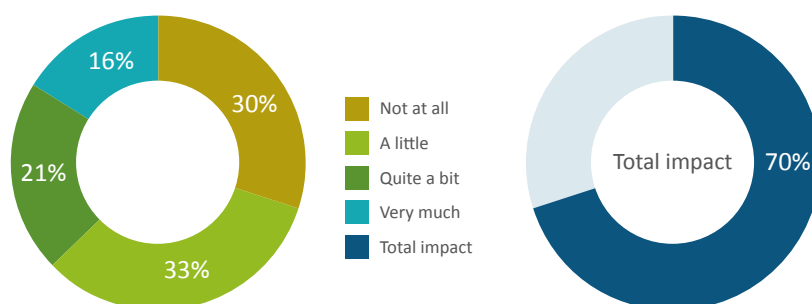
#### 4.4 Quality of life

The survey found that fatigue impacts on many areas of respondents' lives and has a detrimental impact on their overall quality of life.

##### 4.4.1 Daily living activities

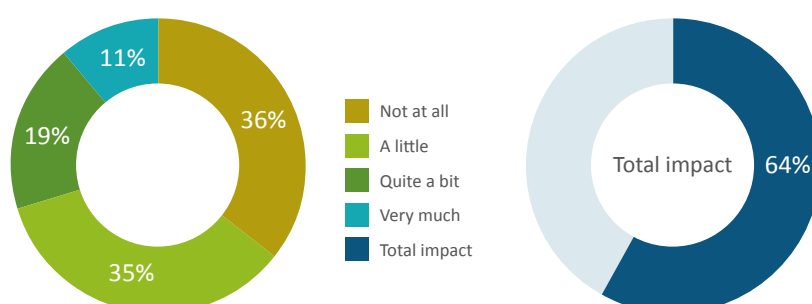
The results suggest fatigue has a significant impact on respondents' ability to undertake simple daily tasks such as bathing and dressing. In total, 70% of respondents said fatigue affected their ability to bath or shower in the past 7 days. 16% of respondents reported that fatigue made it very difficult to bathe, whilst an additional 21% of respondents said fatigue had quite a bit of impact. 11% said their fatigue made it 'very much' more difficult.

Has fatigue made it difficult to bathe or shower?



The results were similar for respondents' ability to get dressed. Overall, 64% said their fatigue made it difficult to get dressed to some extent in the past week. 35% said their fatigue made it a little difficult, 19% said their fatigue made it significantly difficult, and 11% said their fatigue made it very much difficult.

Has fatigue made it difficult to dress yourself?



A higher percentage of those not currently in employment reported difficulties with bathing, showering and dressing than those currently employed: 62% of those in employment said fatigue made it difficult to bath or shower, including 11% who said it made it 'very much' more difficult.

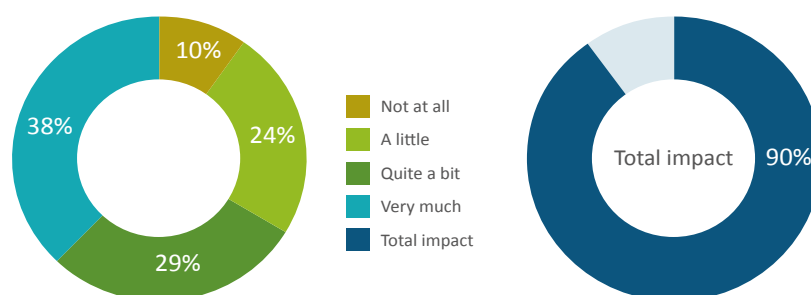
In comparison, 76% of those not in employment said fatigue made it difficult, with 20% reporting that fatigue had made it 'very much' more difficult.

Similarly, for dressing themselves, 56% of those currently in employment said fatigue made it difficult compared with 70% for those not currently in employment. 7% of those in employment said fatigue made it 'very much' more difficult, compared with 14% of those not currently in employment.

#### 4.4.2 Mental health

The vast majority of respondents to the survey (90%) said fatigue caused them to feel down or depressed to some extent. Shockingly, 38% of respondents said they felt 'very much' down or depressed because of their fatigue during the last 7 days and a further 29% of respondents said they felt 'quite a bit' down or depressed. The proportion of respondents with depressive symptoms is higher than other studies, which report between 8% and 46% of people with RA having depressive symptoms<sup>147</sup>.

Have you felt down or depressed because of fatigue?



Of concern, use of psychological services was low among respondents with only 4% of respondents said they used cognitive behavioural therapy to manage their fatigue and 12% said they had spoken to a counsellor or other professional for support because they felt worried or upset because of their fatigue.

Emotional impact was more pronounced in newly diagnosed respondents with RA compared to those with established disease: 44% of respondents diagnosed with RA for less than 1 year said they had been very much down or depressed by fatigue in the past 7 days compared to 32% of those diagnosed for 21 years or more.

Similarly, 49% of respondents diagnosed for less than 1 year reported being 'very much' upset by fatigue in the past seven days compared to 31% of those diagnosed for 21 years or more.

In addition, 80% of those diagnosed with RA for less than 1 year said they cried because of fatigue compared with 70% of those diagnosed with RA for 1-5 years.

A difference was also observed between employed and those not employed: 75% of those employed said they had cried because of fatigue compared with 63% of those currently not employed.

#### 4.4.3 Relationships

70% of respondents said their fatigue prevented them from taking part in activities with their family or partner.

49% said they always felt guilty about the impact of their fatigue on others, and 29% of respondents said their fatigue caused family or a partner to become emotionally upset.

54% of respondents said fatigue had negatively affected their sex life and 8% of respondents attributed the loss of a relationship to fatigue.

“I have two wonderful grandchildren who I cannot play with when I’m fatigued. It’s horrible.”

Has fatigue negatively affected your relationship with your family or partner?  
Tick as many as apply.

	Response (%)
I have lost a relationship due to my fatigue	8%
It has prevented me from taking part in activities with my family and/or partner	70%
It has caused my family and/or partner to become emotionally upset	29%
Fatigue has negatively affected my sex life	54%
None	10%
Don't know	5%

Respondents were more likely to discuss their fatigue with their partners than anyone else: 32% of respondents always discussed it with them and 37% said they sometimes discussed it with them. However, 31% of respondents said they never or rarely discussed their fatigue with family members or friends, and 14% said they never or rarely discussed their fatigue with their partner.

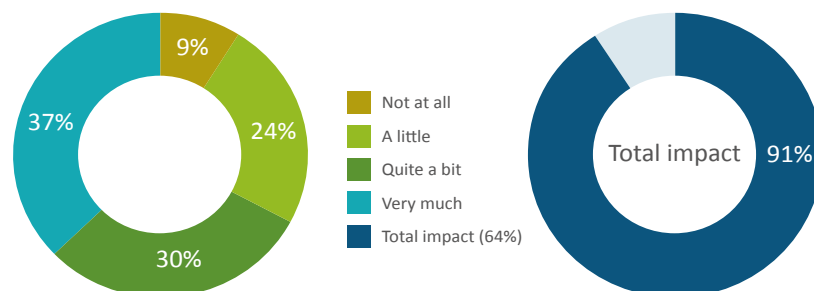
How often have you discussed your fatigue with the following people, if at all?  
Please tick one answer for each person.

	Never or rarely	Sometimes	Always
Partner	14%	37%	32%
Family member or friend	31%	54%	14%
NRAS helpline	76%	4%	1%
Patient organisations	73%	5%	1%
Online forum or online social network	68%	13%	4%
Someone else	60%	15%	2%

#### 4.4.4 Social

91% of respondents said fatigue impacted upon their social life within the last 7 days. 37% of respondents said fatigue ‘very much’ impacted on their social life and 30% said fatigue affected their social lives ‘quite a bit’.

Has fatigue affected your social life?



## 4.5 Fatigue and work

### 4.5.1 Employment status

The average reported level of employment among working age respondents (50%) was higher than the reported average for the UK population (72%)<sup>148</sup>.

Level of unemployment increased with length of time since diagnosis. 33% of working age respondents diagnosed with RA for less than 1 year were not in work, whereas 50% of working age respondents diagnosed for 6-10 years were not in work.

Time since diagnosis	Less than 1 year	1-5 years	6-10 years	11-20 years	21+ years
<b>Respondents in work</b> (working age respondents)	67%	55%	50%	43%	35%
<b>Respondents not in work</b> (working age respondents)	33%	45%	50%	57%	65%

### 4.5.2 Contribution of fatigue to worklessness

24% of respondents said they changed jobs because of their fatigue. The percentage is slightly higher than previous NRAS research, when 18.5% of respondents said they changed occupation due to physical limitations of the disease or fatigue<sup>149</sup>.

The percentage of respondents who said they changed jobs rose slightly with length of time after diagnosis. Only 14% of those diagnosed with RA for less than 1 year said they changed jobs because of fatigue, compared with 22% of those diagnosed for 1-5 years and 27% for those who had been diagnosed for 6-10 years.

In comparison, 71% of working age unemployed respondents said fatigue contributed to their inability to work. The percentage is slightly lower than previous NRAS research, when 79.6% of unemployed respondents reported that chronic fatigue was a major barrier to their employment<sup>150</sup>.

The percentage of working age respondents who said fatigue contributed to their inability to work rose according to length of time since diagnosis: 45% of those of working age diagnosed with RA for less than 1 year, compared to 70% of those diagnosed for 1-5 years.

### 4.5.3 Number of hours and days missed from work

Overall, 31% of respondents took some time off work in the 7 days prior to completing the survey because of problems associated with their fatigue and 10% of all respondents said they missed over 10 hours of work during the same period of time because of their fatigue.

People diagnosed with RA for less than 1 year took a greater amount of time off work in the preceding 7 days because of problems associated with their fatigue: 41% said they had taken some time off and 19% said they missed over 10 hours of work during the last 7 days.



“On days when I work, I can do nothing else; I am completely drained. No one knows this but me. Even thinking about telling anyone makes me cry.”

During the past 7 DAYS, how many HOURS did you miss from work because of problems associated with your fatigue? Include hours you missed on sick days, times you went in late, left early, etc., because of your fatigue.

	All respondents	Diagnosed for less than 1 year
Hours	Response (%)	Response (%)
0 hours	69%	59%
1-10 hours	22%	22%
11-20 hours	4%	8%
21-30 hours	2%	2%
31-40 hours	2%	7%
41-50 hours	0%	1%
51-60 hours	0%	0%
60+ hours	1%	0%
10+ hours	10%	19%
1-60 hours	31%	41%

The majority of respondents (56%) said they took time off work in the past 12 months because of their fatigue. 23% took more than 10 days off and a further 23% also took up to 5 days off during the past year. In total, 33% of respondents met or exceeded the average number of sick days taken by UK workers during a year (4.4).

In comparison, those respondents diagnosed with RA for less than 1 year took more time off from work during the past 12 months because of their fatigue (65%). 42% of respondents diagnosed for less than 1 year met or exceeded the average number of days taken by UK workers (6), with 34% absent from work for more than 10 days.

How many DAYS over the past 12 MONTHS has your fatigue caused you to be absent from work?

	All respondents	Diagnosed for less than 1 year
Hours	Response (%)	Response (%)
0	43%	35%
1-5	23%	23%
6-10	10%	8%
11-20	8%	7%
21-50	9%	13%
50+	6%	14%

#### 4.5.4 Productivity

Not only did fatigue cause respondents to miss work, or take time off from work, but it also impacted on their productivity while at work.

92% of the employed respondents said fatigue had at some level impacted on their work productivity during the last 7 days. 40% said fatigue had a medium impact and 19% said fatigue had a high impact. 5% said fatigue had completely prevented them from working altogether.

#### 4.5.5 Affected work activities

Fatigue impacted significantly upon respondents' ability to undertake activities required for their job. This was true across both physical and mental tasks. However, overall, respondents ranked the physical tasks of crouching, bending or kneeling; standing for long periods of time; and lifting, carrying or moving objects as the most difficult activities to undertake as a result of their fatigue.

The impact of fatigue on transportation, while still significant, ranked as the least difficult to overcome compared to other physical and mental tasks. 59% of respondents said fatigue caused difficulty getting to and from work, including 12% who said it caused a lot of difficulty.

By comparison, 73% of respondents said they experienced difficulty sitting for long periods of time due to their fatigue and 72% reported difficulty lifting, carrying or moving objects because of fatigue. Of particular note, 37% of respondents said fatigue caused them a lot of difficulty with lifting, carrying or moving objects and 16% said they were unable to do this at all, as a result of their fatigue.

In addition, there were two activities that respondents scored highest on total difficulty caused by their fatigue, although the level of difficulty encountered was lower compared to other tasks: working with hands (86%) and concentrating or keeping their mind on work (84%). In the case of both activities, 28% reported a lot of difficulty completing the tasks as a result of their fatigue. However, virtually none of the respondents said they were completely unable to do these tasks as a result of their fatigue.

	No difficulty	Some difficulty	A lot of difficulty	Unable to do
Meeting current job demands	23%	55%	20%	2%
Getting to and from work (e.g., subway, bus, car, walking) and getting to and from work on time?	39%	47%	12%	1%
Getting around the workplace (e.g., stairs, hallways, furniture)?	33%	52%	12%	1%
Sitting for long periods of time at your job (e.g., more than 20 minutes)?	23%	46%	27%	3%
Standing for long period of time at your job (e.g., more than 20 minutes)?	16%	37%	33%	13%
Lifting, carrying or moving objects?	8%	35%	37%	16%
Working with your hands (e.g., writing, typing, grasping small objects, holding a phone)?	11%	58%	28%	0%

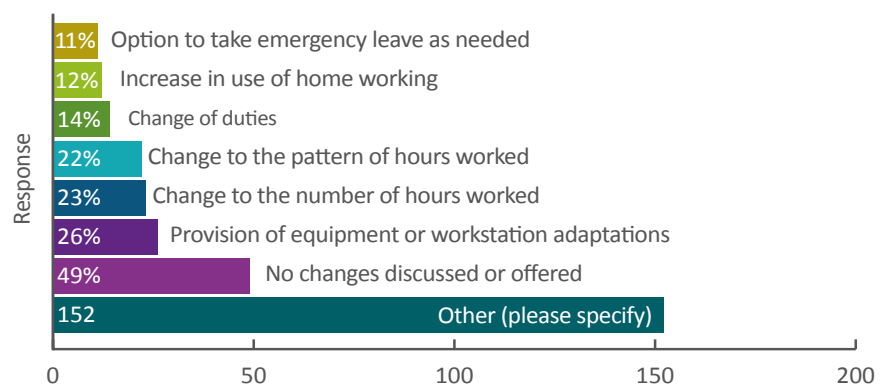
	No difficulty	Some difficulty	A lot of difficulty	Unable to do
<b>Crouching, bending, kneeling or working in awkward positions?</b>	6%	31%	43%	18%
<b>Reaching?</b>	21%	44%	28%	3%
<b>Schedule or hours of work that our job requires?</b>	23%	55%	20%	1%
<b>Pace of work that your job requires?</b>	23%	51%	23%	2%
<b>Meeting your current job demands?</b>	23%	55%	20%	2%
<b>Concentrating or keeping your mind on your work?</b>	15%	55%	28%	1%

#### 4.5.6 Employer support

The results suggest there is a need for improved support from employers, as 49% of employed respondents said their employer or line manager had not discussed or offered changes to help them manage their fatigue.

Of those who had changes offered or discussed, the most common option discussed was equipment or workstation adaptations, with 26% saying this had been offered. 23% said they had been offered changes to the number of hours worked, while 22% said they had been offered changes to the pattern of hours worked.

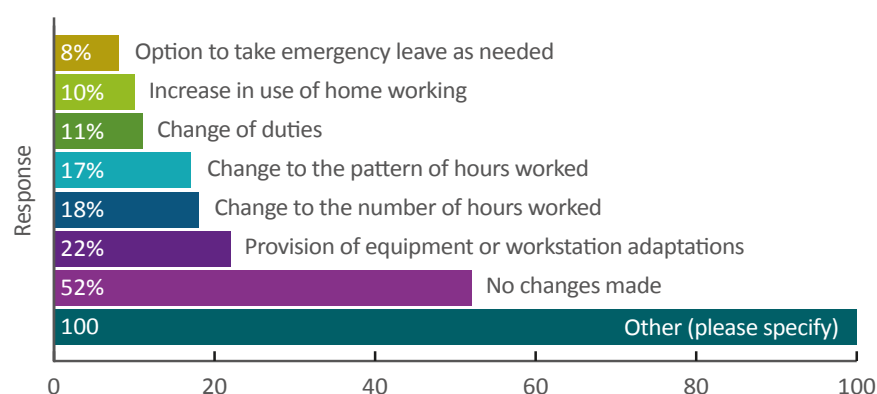
Conversely, only 14% of respondents said a change of duties had been discussed or offered and 12% said they had been offered an increase in the use of home working. Emergency leave was the least common option discussed with only 11% being offered this.



However, 52% of respondents said no changes had actually been made to accommodate their fatigue. When changes were made, respondents reported that the most common action was to adapt equipment or the workstation (22%).

The second most common action undertaken by respondents was to change to the number of hours worked (18%). The percentage recorded was a great deal

lower than a Dutch study, which found that 46% of respondents had reduced their working hours<sup>151</sup>.

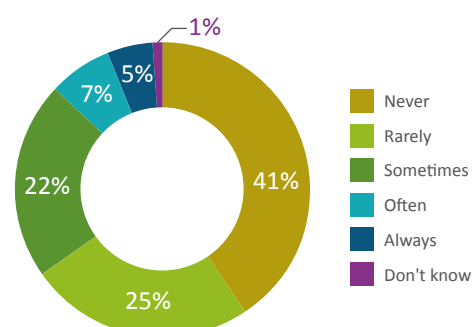


## 4.6 Management of fatigue

### 4.6.1 Discussions about fatigue

66% of respondents said their healthcare professionals never or rarely asked how their fatigue affected them, with 41% specifically saying their healthcare professional never asked at all.

Do your healthcare professionals ask you how fatigue is affecting you?



51% of respondents said they never or rarely spoke to their GPs about fatigue, and 47% said they never or rarely spoke to their rheumatologist or specialist nurse about it.

How often have you discussed your fatigue with the following people, if at all?

Please tick one answer for each person.

	Rarely	Sometimes	Always
<b>Rheumatologist</b>	<b>47%</b>	<b>37%</b>	<b>15%</b>
<b>Specialist nurse</b>	<b>47%</b>	<b>33%</b>	<b>13%</b>
<b>Counsellor</b>	<b>58%</b>	<b>6%</b>	<b>3%</b>
<b>GP or other health professional</b>	<b>51%</b>	<b>36%</b>	<b>9%</b>

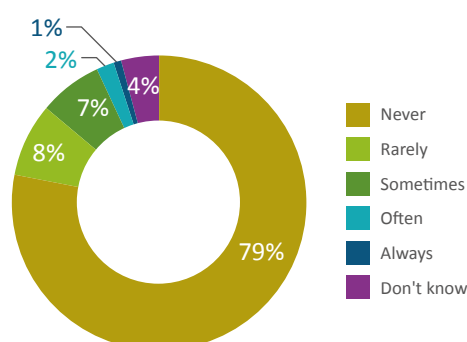
### 4.6.2 Measurement of Fatigue

79% of respondents said their healthcare professional never tried to measure their levels of fatigue and a further 8% said their healthcare professional only rarely measured their level of fatigue.



“I feel as if even the medical profession think I am making up my fatigue. So this just makes me feel worse about it!”

Has a healthcare professional ever tried to measure your levels of fatigue?



## 4.7 What would help

### 4.7.1 Management of fatigue

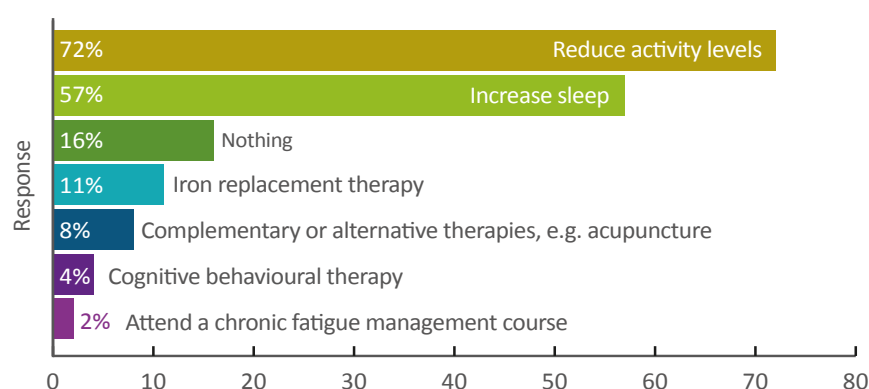
When respondents were asked how they managed their fatigue, the most common strategies deployed were to reduce activity levels (72%) and increase sleep (57%).

Worryingly, the proportion of respondents who said they did nothing to manage their fatigue (16%) was higher than those who had used clinically proven interventions such as attending a chronic fatigue management course (2%) or using a cognitive behavioural therapy (4%).

Iron replacement therapy was used by a number of respondents (11%), even though the literature review suggests there is a mixed evidence base concerning the impact of anaemia and resolving haemoglobin on RA fatigue.

Also of note, those who had been diagnosed with RA for less than 1 year were marginally more likely to do nothing (22%) than all respondents (16%).

How do you manage your fatigue? Tick as many as apply.



### 4.7.2 Support

When asked about support that would help reduce the impact of fatigue, most respondents rated information for patients as very important (90%), followed by public awareness campaigns (81%) and information for family members and carers (80%).

Slightly below this, 74% of respondents said information for employers was very important in helping to reduce the impact of their fatigue. 71% also said the same about information about employee rights.

Finally, 40% of respondents said peer to peer support and 43% said sign-posting to patient organisations were of some importance to helping to reduce the impact of fatigue.

(All respondents):

What support would you like to help reduce the impact of fatigue?

		Very important	Of some importance	Low importance	N/A
1	Information for patients	90%	9%	1%	1%
2	Public awareness campaigns	81%	17%	1%	1%
3	Information for family members / carers	80%	17%	1%	1%
4	Information for employers	74%	14%	1%	11%
5	Information about employee rights	71%	17%	2%	10%
6	Peer to peer support	55%	40%	3%	2%
7	Sign-posting to patient organisations	48%	43%	5%	3%

(Respondents in work):

What support would you like to help reduce the impact of fatigue?

		Very important	Of some importance	Low importance	N/A
1	Information for patients	88%	11%	1%	1%
2	Public awareness campaigns	83%	16%	1%	0%
3	Information for family members / carers	80%	16%	1%	3%
4	Information for employers	79%	19%	1%	1%
5	Information about employee rights	78%	17%	3%	2%
6	Peer to peer support	53%	43%	2%	1%
7	Sign-posting to patient organisations	43%	49%	6%	3%

# 5 Conclusions and Recommendations

## 5.1 Survey findings

- Public awareness of the symptom of chronic fatigue and its impact, as perceived by RA patients, was reported to be very low. This is in line with other evidence in the literature review, which found consistently low levels of public awareness about the symptoms of RA and its impacts (specifically chronic fatigue). Of particular note, nearly two thirds of respondents said that the onset of chronic fatigue happened before they were diagnosed.
- The findings from the literature review documented evidence of the severity of impact that chronic fatigue has on quality of life for people with RA. The results support this view, with almost all respondents reporting to be affected by chronic fatigue, the majority for several days per week, with episodes tending to last several hours and having a moderate or high level of impact.
- The reported social and emotional impacts of chronic fatigue were very high. The vast majority of respondents said that it caused them to feel down or depressed and that it had prevented them from taking part in activities with their family or partner, including a substantial impact within the last seven days.
- Medical guidelines for RA and government strategies for people with long term conditions highlight annual reviews and self-management education as opportunities to effectively manage chronic fatigue. However, the results suggest a substantial gap between best practice and the patient experience. A high number of respondents reported that their chronic fatigue was rarely discussed (if at all), and that they were almost never referred to a chronic fatigue self-management course.
- Despite the development of several validated chronic fatigue scales, described in the literature review, the results suggested that in only a very few cases are these scales actually being routinely used by healthcare professionals to measure and record the impact of chronic fatigue on their RA patients.
- The literature review found that chronic fatigue often has a severe impact on work outcomes for people with RA. The results also support this view, with the majority of working age respondents reporting that their chronic fatigue had contributed to their unemployment and a significant proportion having changed jobs and taken time off work during the previous week because of it.

## 5.2 Recommendations

- In light of existing calls to invest in public awareness campaigns for RA by patients, healthcare professionals, and leading organisations, we recommend that the governments of England, Scotland, Wales and Northern Ireland urgently initiate such campaigns, which must include specific messaging about the presence of chronic fatigue as a symptom of RA.
- We remain concerned that NICE Clinical Guideline 79 and SIGN Guideline 123 governing the management of rheumatoid arthritis underplay the importance of effective management of chronic fatigue and need to be strengthened accordingly. We recommend the regular use of validated chronic fatigue measures during annual reviews (and ensuring everyone has a review), enhanced provision of psychological therapies as part of the multi-

disciplinary team and the introduction of improved protocols for referral to non-pharmacological treatments that can help to reduce the impact of chronic fatigue.

- The role of patient education and self-management strategies is not yet consistently prioritised across relevant medical guidelines and long term condition government policies within England, Scotland, Wales and Northern Ireland. We recommend that more consistent wording is adopted across medical guidelines and public policy and that additional resources are released by governments to ensure the role of patient education and self-management can be fully realised to improve clinical outcomes for RA patients.
- More needs to be done to raise awareness of chronic fatigue amongst employers through provision of information about how current treatment regimens help to reduce fatigue levels, and to inform employers about the significant challenges chronic fatigue can pose when the disease is not well controlled, during the lag time before a patient's treatment starts to work, or when a patient's treatment has recently been switched.
- Assessment of chronic fatigue, which has a strong impact on work outcomes, is notably absent from the descriptors in the ESA's Work Capability Assessment. We believe this is a significant omission and therefore recommend an additional descriptor is introduced into the medical assessment to ensure the impact of chronic fatigue on people with RA is adequately captured and reflected in decisions to award the ESA benefit.

# 6 Thank you

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